

# Time is money—or is it?

## Estimating the costs of informal caregiving

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In this issue of *Neurology*, Hickenbottom et al. estimate the annual costs of informal care for elderly patients with stroke in the United States to be \$6 billion.<sup>1</sup> This estimate was based on interview data from a representative cohort of the community-dwelling US elderly population aged 70 and over. This estimate would presumably be higher if younger community-dwelling patients as well as institutionalized patients (many of whom receive some unpaid caregiving) were also included. Nevertheless, informal caregiving costs for stroke would not likely exceed 20% of the recent estimate of \$43 billion for other direct and indirect costs of stroke care in the United States.<sup>2</sup>

In deriving their estimate, the authors make several assumptions: 1) respondent (or proxy) reports of physician-diagnosed stroke are accurate; 2) respondents (or their proxies) accurately report the hours of informal care; 3) statistical adjustment for various covariates associated with the use of informal care allows accurate quantification of the additional hours of informal care attributable specifically to stroke; 4) all individuals surveyed live a full year, and their informal caregiving is constant over the year; and 5) the opportunity cost of informal caregiving provided by a retired elderly person is the same as the national median wage for a home health aide. Although these assumptions could be tested and refined, the authors' assumptions are typical of similar studies for other conditions (e.g., AD). Certainly, the authors' estimate of less than 3 hours of informal care a day (and less than 2 hours a day for the additional care attributable specifically to stroke) does not seem exaggerated, and is less than most estimates of similar care for patients with AD.<sup>3–5</sup>

Although attempts to estimate the costs of informal caregiving for stroke and other aging-related disorders are laudable, it is difficult to interpret the results. They are based on mathematical models, with various (often unstated and untested) assumptions, that estimate "societal" dollar costs for services

presently provided with remuneration, and that include different components in the modeled costs. If the services had to be purchased, the estimates are reasonable expectations of costs. However, because they are not purchased, and because much of the care is provided by persons no longer in the employed workforce, interpretation is not straightforward. Moreover, other studies of the impact and burden of caregiving for long-term stroke survivors have noted caregiver "costs" well beyond those attributable simply to the hours of custodial care provided—costs not considered in the estimates by Hickenbottom et al. The costs include adverse effects on caregivers' emotional and physical health, social activities, leisure time, and family relationships.<sup>6–8</sup> Assigning a dollar value for these component costs is a difficult and complex task, and the resulting cost estimates for informal caregiving are dependent upon which components are included and how they are valued.

When escalating (direct care) national healthcare costs are discussed, it is common and reasonable to compare them to the gross domestic product (i.e., the value of all goods and services produced in a country as calculated by adding personal spending, government spending, investment, and net exports). However, unpaid informal care services are not considered as part of the gross domestic product, and must therefore be part of some larger (and as yet undefined) universe of goods and services. In this larger universe of goods and services, are all unpaid non-leisure hours to be valued at a rate based upon some surrogate workforce value (e.g. minimum wage, mean industrial wage), or just those hours devoted to care for some disease (e.g., median health aide wage)? Costs are seldom measured in this way for many other activities that require unpaid non-leisure work hours (e.g., childcare, home ownership, charitable community activities), especially when those activities do not interfere with employment. If some or all unpaid non-leisure hours are valued in

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dollar terms, what is the most appropriate value: some function of the foregone earnings lost because of disease, some function of replacement costs, or some imputed value of life itself?<sup>9,10</sup> Is there an approach that can be agreed upon, and that will be widely applicable, or will individual studies continue to make individual (if reasonable) assumptions? In the absence of consensus, estimates will vary widely.

Perspective is a critical, but often implied, element of cost assessments. For example, US governmental priorities in discussions of healthcare expenditures usually involve minimizing components of the direct costs of care (i.e., specifically those costs that the government must reimburse), or in providing relief for selected tangible out-of-pocket costs to citizens (e.g., healthcare insurance, medication costs, long-term institutional care). The government does not “pay the bill” for informal caregiving, nor do third-party payers, so such costs are often overlooked in national health policy debates. In contrast, individual patients are less concerned about the components of total direct costs that are borne by the government or third-party payers. Instead, patients care most about their own out-of-pocket expenses (e.g., insurance costs, deductibles, copays) and their own indirect costs (e.g., lost wages, caregiver burden).

The “societal” perspective, often advocated by economists, attempts to measure and weight all direct and indirect costs. For many chronic and relatively intractable disorders, investigators and pharmaceutical companies often pursue studies aimed at such a broad universe of “costs” in the hopes of demonstrating “cost-effectiveness” of new therapies. The costs of a therapy under investigation are weighed against the modeled costs to society that would otherwise be incurred in the absence of treatment. The various stakeholders are like blind men feeling different parts of an elephant—not one of them really has the global picture of costs that the model does, and each of them judges the costs from their own narrow perspective.

Another problem with this “societal” perspective is that the modeled cost-effectiveness of a treatment may depend on estimates of decreases in indirect costs only, or at least may be swayed heavily by these weighted indirect costs. Such circumstances can produce a paradox, because adoption of such a “cost-effective” therapy may produce increases in direct-care costs for all stakeholders. These include the government (and ultimately the taxpayers),

third-party payers (and ultimately those that pay the premiums, including individuals and employers), as well as individual patients and their caregivers (who will have to bear some direct costs of the new treatment). Whether the tradeoff is worth it depends on a complex calculus with different components and different weights in each case.

No matter which perspective one adopts in estimating costs, a careful assessment of the underlying assumptions of any model is necessary to sensibly interpret the results and to use them for rational decision-making. If one critically examines the assumptions, one may consider the derived estimates as either overly optimistic or pessimistic, depending on one’s point of view, but at least they will help anchor subsequent discussions and move decision-making incrementally forward. The reality is that resources are limited, and therefore choices must be made to allocate them. Costs are best avoided no matter how they are measured.

So are we better off having cost estimates? Certainly. Should we accept them at face value? Certainly not.

## References

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